

Find Sarah on the Net

Find the first three parts of Sarah's Second Chance and an audio and photo presentation at www.monroepublishing.com/sarahsstory. The Gravels' online family journal of Sarah's experience is available at www.caringbridge.org/mi/sarah.



Doctor: Living wills confusing

Dr. Ferdinando Mirarchi, a Western Pennsylvania emergency room physician, said that living wills, which are not legally recognized in Michigan but often used to supplement the state's accepted do-not-resuscitate form and power of attorney for health care form, are misinterpreted by medical staff 99.9 percent of the time because they are written in legal terms, not medical terms. Living wills legally are recognized in 48 states and used by medical personnel in those states to guide care decisions.

Your Health

A guide to better living through fitness, medicine, diet and wellness

section
C
THE MONROE
EVENING NEWS
TUESDAY
JULY 26, 2005

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The Monroe Evening News



Michelle Gravel (center) reviews the large bags of medications and other medical supplies with nurse Lori Amos while the family prepares for Sarah's discharge from UM Mott Children's Hospital in Ann Arbor.

A new life at home

Six-year-old Sarah Gravel, recovering from a liver transplant, is released from the hospital to a different world than she knew before.

STORY BY STACY KESS ■ PHOTOS BY KIM BRENT

It only took two hours for a liver to become available for 6-year-old Sarah Gravel, who had spent most of her life with a liver torn apart by neonatal hepatitis. Doctors transplanted a healthy liver into her abdomen during a six-hour procedure. The recovery process also seemed to move quickly — until tests indicated she had an infection.

Sarah's mother, Michelle Gravel, remained by her daughter's side throughout the recovery, while her father, Ron Gravel, stayed at home in Monroe caring for her brother, Jacob, and sister, Anna. Sarah's grandmother, Maureen (Baba) Palmer, visited as often as her schedule would allow. As the days passed, Sarah continued her campaign to return home in time for Anna's third birthday May 26.

A Monroe Evening News reporter and photographer documented Sarah's homecoming and transition into her new life.

3:30 p.m. May 25, C.S. Mott Children's Hospital, Ann Arbor, fifth floor west, Room 514

"Don't worry," Michelle said, smiling at her husband. "I'm not going to forget anything."

Just after 2 p.m., the nurse told Michelle that she and Sarah were going home. Ron already was on his way for a visit and arrived about 3 p.m. to good news and a room buried in cardboard boxes, blue bags labeled "Patient Belongings," stuffed animals and Sarah's artwork.

Sarah pushed another stuffed animal into an already-brimming box, closing the lid as best she could. She grabbed a marker and looked up inquisitively. "How do you spell 'animals?'"

Ron rattled off the answer: "ANIMALS."

Sarah danced around the room, laughing. Although the tubes remained in her hands, she was not attached to any IVs. It wouldn't be long before those, too, were gone. Each step forward was a step closer to home.

"So long as I can sleep in a people bed and eat people food," Michelle said, sighing. "I was really hoping she could at least get out today. I mean, Anna has no clue it's her birthday (tomorrow), but we do."

Sarah especially was aware of that fact, spending much of her time drawing pictures, painting carved wood animals

See SARAH, Page 2C



While the family awaits final discharge paperwork and removal of Sarah's remaining IV lines, Ron and Sarah (above) play together in the arts and crafts room, one of the few places Sarah enjoyed in the hospital. Nurse Lori Amos, Sarah's first and last nurse at Mott Hospital, waves goodbye (below) as the Gravels leave the fifth floor ward for their Monroe home. Sarah must wear a mask for protection from germs until she is out of the hospital.



SARAH'S SECOND CHANCE

July 5 — Part 1: On the waiting list

July 12 — Part 2: The night before

July 19 — Part 3:

A new liver, a new lease

Today — Part 4: A new life at home

FROM PAGE 1C

Sarah (cont.)

and setting aside stickers for her little sister, which she stuffed in boxes and bags around the room. She declared herself done with packing and escorted her father to the arts-and-crafts room next to her hospital room.

"We came with a duffel bag," Michelle said. "I'm just so glad to be leaving ... We've been together so much through all her illness. She's always by my side. Maybe it was just reconfirming she's silly and she's sweet and way too smart."

She paused. "I learned how strong she is."

In the arts-and-crafts room, Sarah sat opposite her father at a short table, making her dad appear like a giant. She slapped paint on a star, part of a project that involved most of the children in the ward in celebrating the "American Idol" finale.

Ron watched her, smiling serenely.

"I've realized how important she is and how bad it would be if she wasn't around," he said. "I've realized how important I actually am to her."

Michelle sat down next to her husband, the packing in Sarah's room finished. "I've put myself aside for the whole week. There hasn't been 'self' since last Friday."

5 p.m., Mott Hospital, fifth floor west, Room 514

Bottle by bottle, a nurse handed Michelle Sarah's medications from a large bag.

"Holy cow," Michelle gasped.

Ron's eyes widened. "Oh my gosh. Sarah's pharmacy."

In all, Sarah was instructed to take 14 medications — 10 pills and four liquids — each day to help her body adjust to the transplant. In all, she would take 20 doses a day. Although many of the medications will be tapered off eventually, she always will remain on anti-rejection drugs and a regimen to ensure the foreign liver functions in Sarah's body.

"Look at this, Sarah," Michelle cooed. "This is all for one little 6-year-old girl."

"I don't want a lot of medicine," Sarah pleaded.

After nearly 10 minutes of discharge instructions, the nurse turned to Sarah with the words she had waited to hear: "We need to take that IV out, Sarah."

After a moment of struggling with the well-taped IV, Sarah was free, sporting a new Looney Toons Tasmanian Devil bandage on her hand.

"Sarah," nurse Lori Amos announced, "You get to leave."

With a pale yellow mask covering her nose and mouth to protect her from germs, Sarah marched out of the hospital room she had occupied for more than a week, her parents following with boxes and bags.

6:04 p.m., US-23 South, Ann Arbor

"I like it when we're not in the hospital," Sarah said as the gray Ford Taurus borrowed from Michelle's father rumbled down the freeway, brimming with artwork made by Sarah during her recovery.

"Me, too," Michelle agreed.

Sarah repeated the sentiments to Baba over the cell phone. When the conversation ended, she declared herself bored and began another drawing.

6:36 p.m., I-275, exit 2, Ash Township.

Sarah squealed with excitement as the car turned south on Telegraph Rd. toward Monroe and the family's apartment.

"We're closer," she cried. "Yeah, we're getting closer," Michelle said.

Sarah pointed to each passing landmark, cheering, "Yay."

"Just think, last Friday when we left, it was all dark and rainy, and now it's sunny and warm," Michelle said.

"Is it almost summer?" Sarah wondered aloud, then quickly returned her attention to the signs of home.

"Excited?" Michelle inquired. Sarah responded with a nod.

"Me, too," Michelle said, yawning.

At 6:45 p.m., the family pulled into their apartment complex off Stewart Rd.

Sarah looked at the rows of tidy brick town houses. "It seems like I've been gone so long."



With Ron leading the way, Sarah and Michelle walk hand-in-hand out of UM Mott Children's Hospital, where the two had spent nearly a week and a half after her liver transplant surgery.



Sarah talks on the phone with her Baba, her grandmother Maureen Palmer, as the family pulls out of the University of Michigan Hospital complex, finally heading for home.



When the family arrives home, the three Gravel children, Jacob, Sarah and Anna, immediately join together in a "welcome home" hug, as their great-grandmother (left) and grandfather Don Cleveland watch.

“ Get well Sarah, feel better Sarah. I miss you.”

— Afternoon kindergarten class, Raisinville Elementary School

6:55 p.m., Gravel home, Stewart Rd., Frenchtown Township

For almost a week and a half, the apartment had been quiet. Within minutes of Sarah's arrival, it filled with noise and excitement as Sarah, Jacob and Anna joined in an impromptu celebration.

Sarah quickly read through a colorful pile of construction paper cards sent by her kindergarten class.

"Get well Sarah, feel better Sarah," she read. "I miss you."

"You have a boyfriend, you have a boyfriend," Jacob sang, dancing around his sister.

"Anna, I have a present," Sarah called.

Anna clapped her hands and cried out with excitement.

"Rocks," Sarah explained, handing her a bag of clay beads.

She picked up a painted wood cutout of a pig. "Anna, I have another present for you. A pig."

"My pig," Anna exclaimed, her voice rising with excitement. "Thank you, Sarah."

The presents continued, some for Jacob and most for Anna. When the distant song of the ice cream truck was detected, Anna's and Jacob's squeals snuck in between the noise of conversation. Sarah quietly asked for ice cream, a little uncertain in a situation she had not seen for nearly two weeks.

"It's been so quiet around here," Ron said with a strained smile. He had attempted to keep the house spotless while Sarah was in the hospital, but the living room already had disappeared under drawings, toys and homemade greeting cards. "It will (return to normal) shortly."

"Mama, please," Jacob pleaded as the ice cream truck grew nearer.

"It's coming," Anna gasped. "Yeah, it's back to normal." Ron chuckled. "Situation normal: out of control. I'm just glad to have them home. I just kind of realized how important I am to her."



With her activity still restricted, Sarah often spends time indoors, playing and watching videos, such as the 3-D movie she and her brother, Jacob, watched one afternoon in early June.

He leaned back in the armchair, looked over Michelle and smiled, then looked back at Sarah, who had joined her sister and brother in the window

anxiously awaiting the ice cream truck. "Before, I thought it was just Michelle and Sarah, but I'm a part of it too."

See SARAH, Page 3C



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Once the family was settled on the night of Sarah's homecoming, their initial hugs and kisses exchanged, Sarah read through a stack of well-wishing cards made by classmates in her kindergarten class at Raisinville Elementary School.



As the children's bedtime approaches on Sarah and Michelle's first night home from the hospital, Michelle and Ron talk in the kitchen. Michelle looks through the large bags of medication — 14 in all, each taken at least once a day totalling about 20 doses — and tries to organize the schedule to administer each of them.

“ I've realized how important she is and how bad it would be if she wasn't around. I've realized how important I actually am to her.”

— Ron Gravel, Sarah's dad



The day after returning home from the hospital, Sarah bolted out the door when she heard the familiar song of the ice cream truck, which she had watched longingly the night before through the window. A neighborhood friend scooped Sarah up, with her arm around Sarah's stomach, to take Sarah back to Michelle. Michelle ran toward them, alarmed about the contact with Sarah's stitches. Michelle reveals Sarah's taped stitches and explains to the neighborhood children (clockwise from top left) Ashlyn Miller, 6, Kionna Richards, 8, William Miller, 5, and Kiara Allen, 6, that they must be careful when playing with her daughter while her stomach heals.

FROM PAGE 2C

Sarah (cont.)

2:40 p.m. June 8, Gravel home

Sarah wandered around her bedroom.

“It was fun coming home, because I don't want to stay at the hospital,” she said, picking up a stuffed animal, examining it and setting it down.

“I got a bad (liver) and it was too bad. I was yellow,” she said.

She held her arms out in front of her stomach. “My belly was like that big.”

“I don't like being yellow... because the other kids made fun of me on the bus.” She stopped in front of her pink plastic storage bins and looked up thoughtfully. “They did. I just ignored them.”

She pulled out a coloring book, “It's Good To Be Me: The Story of My Transplant.” The book asked her to tell about her feelings. “Different,” she answered it in red marker.

“My life is,” she began in purple, then switched to yellow, “different.” In blue, she added, “And it's funny that I have a new liver.”

She looked up from her colorful essay to explain: “I'm so used to having a bad liver.”

3:30 p.m., Gravel home

The Gravels' kitchen was filled with boxes of T-shirts, all printed with the slogan “Don't take your organs to heaven, heaven knows we need them here.” Although Sarah's surgery was three weeks in the past, the family's fundraising effort continued with T-shirt sales and collection jars at local businesses. Baba, bubbling with ideas and energy,

remained the mastermind behind the fundraisers. She and other family members planned to sell T-shirts for \$10 at the Redford Township Festival.

“We're promoting organ-donor awareness,” Baba said. “I think a lot of people just have no idea. People think ... it costs money to donate. There's no cost. You're giving of yourself.”

Sarah's daily life had less to do with fundraisers and more to do with medication. Medication maintained her new liver, which, according to all tests, was working well. Her stitches were nearly healed. She had taken off her own bandages weeks earlier, leaving a brown frown of a scar on

her now-flat belly. Her skin had taken on a healthy pink hue and her hair had begun shedding the silver and gold highlights brought on by the jaundice with which she once had lived.

Sarah's personality had begun to change, too. Although often silly around her family, she once had refused to talk in front of strangers. After coming home, she became vocal and loud, much more like other children her age. She adopted new fashion sense, too, begging her mother for only the trendiest clothing when the two went to buy clothes that fit Sarah's new body.

While Sarah played with her siblings, Michelle and her

mother rested at the kitchen table.

“I said I thought her liver came from a funny little girl who is really into fashion,” Michelle said after an afternoon of swimming with her three children.

“She's an absolute nutcase now,” Baba nodded. “She's just on all the time.”

Personality changes in transplant patients are possible, according to Sarah's surgeon, Dr. John Magee. Sarah's body was working well and acting healthy for the first time. She was taking prescription steroids and finally had a non-jaundiced appearance. Any such situation could have caused changes in her.

“She's just extra silly,” Baba

said. “Extra giggly.”

“They lowered her steroid level yesterday,” Michelle said, throwing her arms up in a silent cheer.

“She's never known anything but being sick,” Baba said. “I think it's like all of a sudden she's just a normal kid.”

4:30 p.m. July 1, Claire's Boutique, Frenchtown Square mall

“I'm going to get pink flow-

ers,” Sarah announced from her perch on a bench outside Claire's Boutique.

The pink flowers marked a milestone in her recovery. Sarah's body was healthy enough for her ears to be pierced, a procedure that had been put off until July to give her time to heal enough to allow two new wounds, which would be an infection risk.

See SARAH, Page 4C

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While the children play upstairs, Michelle takes advantage of some down time to continue work on the donation jars that she and her mother leave with local businesses. The family work to help defray expenses related to Sarah's medical care is an ongoing project for the Gravel's.



Sarah turns to make another run down the sidewalk as she takes her first bike ride since her surgery. Doctors initially restricted her activity, afraid of excess stress on her body, belly and healing stitches. Seven weeks after the transplant, Sarah is finally allowed to enjoy typical childhood activities.



Sarah plays in the toy chest at the Blue Bush Branch Library as Michelle reads to Anna. The Gravel children love to read and visit the library several times a week. Prior to her surgery, Sarah declared that she wanted to become a librarian someday.

FROM PAGE 3C

Sarah (cont.)

"I'm going to sit on Daddy's lap," she said, but her attention shifted quickly to the next exciting piece of news. "We got a van today."

After months of borrowing Michelle's father's car, the family finally had raised and saved enough money to buy a used van to transport Sarah and her siblings to the University of Michigan for Sarah's doctor appointments.

Sarah watched intently as two Claire's employees readied the equipment to pierce her ears. There would be other milestones to come: a first bicycle ride since her surgery, reductions in medications, six-month and one-year checkups. She sank into Ron's lap as he sat on the tall stool at the entrance to Claire's.

"We need you to hold really, really still," the store manager told Sarah, holding the piercing gun up to a tiny dot on her ear.

"One, two." The piercing guns clicked, pressing small pink jewels into Sarah's ears. "All done."

8 p.m. July 18, Gravel home

As Sarah took her night medicine, Michelle noticed something was wrong: Sarah's skin was warm to the touch and she had a headache. When the thermometer read 102 degrees Fahrenheit, Michelle called UM Mott Children's Hospital. She was instructed to bring Sarah into the emergency room.

9:55 a.m. July 20, Mott Children's Hospital, 5-West, Room 5682

Sarah sat on her hospital bed, her legs crossed underneath her pink-checked My Little Pony hospital gown. She colored and chatted as if nothing had happened — not the

return to Mott Hospital, not her fever spiking to 104.5 degrees the night before.

"It's only 100 today," Michelle calmly explained. "To me, that's not even a fever."

"And I threw up," Sarah volunteered.

Sarah's left hand was hidden under a mess of tape and IV tubes leading to a bag of potassium chloride hanging from an IV pole high above. Her arm lay useless at her side, taped to a board to stabilize her hand and prevent the tubes from moving.

"As long as it's not her liver," Michelle added, ever stoic in the face of her daughter's health tribulations. "I mean, I'd rather her not be sick, but ..."

She trailed off and watched her daughter giggle and play.

Once again the family was dispersed across southeast Michigan: Sarah and Michelle in Ann Arbor; Anna and Jacob at Baba's house and Ron alone in the family's Monroe home when not on the road to or from his new job in Toledo.

The quiet at home was hard on Ron, who worried and waited, thinking of the previous week when Sarah had learned to ride her bicycle without training wheels and had proudly completed a stack of second-grade flash cards. He called early in the morning to check on Sarah and Michelle and called again just before 11 a.m.

"Mama, I want to go home," Sarah announced

when Dr. Najeeb Zouri entered the room.

"So do I," he told her.

He explained that her fever was gone, but he was ordering several nasal and blood cultures, a task that would fall to a nurse who would have to battle Sarah's screams of discomfort. The cultures would look for viruses and bacteria and allow doctors determine how to best treat Sarah. In the meantime, she would continue to take three antibiotics.

"Mama, I want to go home," Sarah repeated.

"No," Dr. Zouri insisted. "You're going to go home, but maybe tomorrow."

11 a.m. July 21, Room 5682

Although all the cultures came back negative for both viruses and bacteria, Sarah's fever returned to 101.5 degrees. She was ordered to stay in the hospital until she remained feverless for at least 24 hours.

Friday night, after doctors had written new orders for medications and blood work throughout the day, the order was given to let Sarah go home. Her body temperature had remained normal throughout the day and her other symptoms, including a cough and headache also were gone. With a final diagnosis of viral pneumonia, Sarah was released at 7:30 p.m.

She has not returned to the hospital since.

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